



Michigan Department of Health and Human Services

# Newborn Screening News

Winter 2018

*The Michigan Department of Health and Human Services (MDHHS) Newborn Screening Follow-up Program works together with the State Newborn Screening Laboratory and coordinating centers to find and treat infants who need early medical care.*



## ***NBS Quarterly Reports and Stellar Performance***

During the third quarter of 2017, nine hospitals met all six of the NBS performance goals. We would like to congratulate the following hospitals on their impressive efforts!

- Beaumont Hospital—Troy
- Beaumont Hospital—Trenton
- Community Health Center of Branch County
- Lakeland of Niles
- McLaren Port Huron
- McLaren Port Huron—SCN
- Memorial Health Care
- St. Joseph Mercy Hospital—NICU
- Sturgis Hospital

### Performance Goals for NBS Quarterly Reports

1. <2% of screens are collected >36 hours after birth
2. >90% of screens arrive in the state laboratory by the appropriate day
3. <1% of screens are unsatisfactory
4. >95% of electronic birth certificates have the NBS card number recorded
5. >90% of specimens have a returned BioTrust for Health consent form that is completed appropriately
6. >90% of newborns with a dried blood spot have pulse oximetry screening results reported

**We hope you will be able to use information in the quarterly reports to improve your part of the NBS system.  
If you have any questions, please call the NBS Follow-up Program at 517-335-4181.**

### Reporting Missed CCHDs

As you know, the Newborn Screening Program collects individual-level data on the pulse oximetry screening for critical congenital heart disease (CCHD). It is important for the program to collect this data, so we are able to assess the efficacy of the screen and ensure that infants who fail their screen are receiving appropriate follow-up care. Occasionally, a newborn who passed the screen is later diagnosed with a CCHD. If you are aware of this happening, please report this to the Newborn Screening Program. The program will use this information for quality assurance purposes. You can report this to the Newborn Screening Program by emailing Kristen Thompson, Newborn Screening Coordinator, at [thompsonk23@michigan.gov](mailto:thompsonk23@michigan.gov). Thank you so much for all that you do for newborns in Michigan!



#### NBS Follow-up Program Contact Information

Phone: 517-335-4181

Email: [newbornscreening@michigan.gov](mailto:newbornscreening@michigan.gov)

## Reminders about Newborn Screening Refusals and Directives

Although rare, parental refusals for bloodspot newborn screening do occur. If parents refuse newborn screening, hospitals should have the parents sign a document that indicates they have been informed of the risks to their newborn if screening is not completed. A sample document is available in Appendix 7 of the “Newborn Screening Guide for Hospitals”, available on the NBS website ([www.michigan.gov/newbornscreening](http://www.michigan.gov/newbornscreening)). Every hospital should customize the document for its facility and have it reviewed and approved by the legal department. After the parents have signed the document, fax it to the NBS Program (517-335-9419 or 517-335-9739). The list of parental refusals is reviewed by our NBS technicians before reaching out to NBS coordinators about potentially missed screens.

Please make your staff aware that there is a new directive form called the “Residual Newborn Screening Blood Spot Directive”. Using this form, parents can select from the following options:

- Destroy **all** remaining blood spots
- Destroy **only** the portion of blood spots stored for research use
- Store but **not** use blood spots for research after newborn screening is complete.

This form is available on the Michigan BioTrust for Health website.

## Specimen Drying



NBS specimens should be dried for a minimum of three hours in a horizontal position that allows for good airflow. This can be achieved by using a drying rack such as the one illustrated here or by propping the specimen on the cardboard protective flap and placing it on a horizontal surface. Care should be taken to avoid letting the specimen come in contact with the protective flap while drying since this can damage the filter paper and lead to inconclusive results.

Some hospitals have found that the cardboard rack illustrated above tips over easily and does not hold up after repeated use. You may be able to use a file folder rack turned on its side or mounted to the wall, or a rack such as the one shown here used by Genesys Regional Medical Center:



Photo credit: Genesys Regional Medical Center

## Impact of Mistakes that Result in Early Specimen Errors

Early newborn screening (NBS) specimens are those specimens collected at < 24 hours of age. A repeat NBS is requested for the infant in these cases. An Early specimen collection is essential if the infant needs to have a transfusion started or if the infant is being transferred from a birthing hospital to an NICU. In those cases, the specimen must be drawn early and the collection age is accurate.

Unfortunately, many of these Early cases are being created due to errors in filling out the dates on the NBS cards. In 2017 (1/1/2017 - 11/30/2017) there were 2,223 Early cases. Of these, **1,060 (48%) were due to errors** in filling in the specimen collection date/time or birth date/time on the demographic form.

When an Early case is created, the submitting hospital is faxed an Early notification letter (unless the baby is known to have been transferred). There is space at the bottom of this letter to make corrections on the dates and times of birth and specimen collection.

✓ *\*Note: If your records indicate this specimen was collected at => 24 hours please provide the following information and fax back to 517-335-9773 so that we may correct our records on this infant.*

Birth Date: _____	Birth Time: _____ <small>(Military)</small>	Collection Date: _____	Collection Time: _____ <small>(Military)</small>
Name of person completing this form: _____			
**** PLEASE DO NOT FAX PAGES FROM THE MEDICAL RECORD ****			

The letter should be faxed back to the NBS lab at 517-335-9773. **These corrections need to be made and returned within 24 hours so that the scientists have the correct age for interpreting**

**results for analytes with age-related cutoffs.** If the correction is not received within 24 hours, then the Early notification letter is sent to the physician of record on the NBS card, and a repeat NBS blood spot collection is requested on the infant.

It is very important to have time/date corrections made before the Early notification letter is sent to avoid burdening a family with taking their infant back to the hospital unnecessarily to be poked again. Delays in returning an Early correction have also caused positive results to be reported out, resulting in unnecessary alarm and stress on families.

If an Early correction is sent in after the disorder results have been reported, an updated NBS report must be created and sent with a cover letter to the Submitter. Preparing and documenting these updated reports, letters and changes takes approximately 30 minutes for laboratory staff for just one specimen.

In summary, please follow these two important steps:

1. Review your facility's process for documenting birth date/time and specimen collection date/time to verify that accurate information is reported to the NBS Program. The "Completing the Newborn Screening Card" section in the Newborn Screening Guide for Hospitals says, **"It is extremely important to fill out the NBS card completely and accurately. The specimen submitter is legally responsible for the accuracy and completeness of the information on the NBS card."**
2. When your facility receives an Early notification letter, please take the time to review the date/times and return any corrections within 24 hours.

Your help will ensure that infants do not have incorrect results reported out or have an unwarranted repeat screen collected. Reducing errors in date/times will save staff time in reviewing Early notification letters, lab staff time in creating updated reports, and most importantly avoid causing unnecessary stress on Michigan families.

**The Newborn Screening Program held two trainings for hospital staff in 2017:** one in Lansing on October 5 (with a webinar option) and one in Detroit on October 25. Topics at the trainings included an explanation of the data elements collected on the newborn screening card and their importance to the laboratory scientists, guidance for staff to map the newborn screening process at their facility, a detailed overview of the quarterly quality assurance reports that are sent to hospitals, and a patient testimony. McLaren Greater Lansing and Beaumont Trenton Hospitals gave presentations on their newborn screening best practices. Approximately 120 health professionals registered for one of the trainings, representing 44 hospitals across Michigan. Thank you to all who attended a training! If you have suggestions for topics you'd like included in next year's training, please email [newbornscreening@michigan.gov](mailto:newbornscreening@michigan.gov).

#### Holiday Pick-up Schedule: Monday, February 19 (President's Day)

##### Lower Peninsula Hospitals:

- STAT **will** pick up your NBS specimens following the **Sunday pickup schedule**

##### Upper Peninsula Hospitals:

- UPS will pick up your NBS specimens following your regular schedule

NBS Laboratory and Follow-up staff will be working on Monday, February 19.

**Submitter Code:** Please remember that staff members need to record the correct hospital submitter code on the newborn screening card. The last digit indicates the type of nursery: 0 means regular nursery, 1 means NICU, and 2 means SCN. The submitter code is used to make separate quarterly reports for each unit, so it's important that we can correctly identify which unit submitted each specimen.

**Phone Number:** Please remember only one phone number per provider should be listed on the newborn screening card. Many requestors are using cell phone numbers or multiple different phone numbers for lines in provider offices and the laboratory is receiving new entries every day. Please have hospital staff clean up these lists and include one phone number per provider. Only include on the newborn screening card the doctor who is in charge of the baby's care when the baby leaves the hospital.

**Birth Weight:** Please remember to record birth weight in **grams** on the first sample newborn screening card. Enter the current weight in grams on the repeat sample card.

#### TECHNICAL ASSISTANCE

Lois Turbett, NBS nurse consultant, is available to work with staff in any hospital that requests help with specimen collection. She can be reached toll-free at (866) 673-9939 or by email at [turbettl@michigan.gov](mailto:turbettl@michigan.gov) to answer your questions. Kristen Thompson, NBS Coordinator is also available to work with hospitals on CCHD pulse oximetry screening and reporting and can be reached at [thompsonk23@michigan.gov](mailto:thompsonk23@michigan.gov). Together we can achieve our goal that all children diagnosed through newborn screening receive prompt and careful treatment in order to live the healthiest lives possible.

**Please remember to share the quarterly newsletter with staff!**

If you have questions please contact the NBS Follow-up Program at 517-335-4181 or [newbornscreening@michigan.gov](mailto:newbornscreening@michigan.gov) or visit our website at [www.michigan.gov/newbornscreening](http://www.michigan.gov/newbornscreening)